

On January 18, 19, and 20, 1990, over 250 people gathered to discuss and recommend actions needed to revitalize the dream of the Lanterman Act. These Californians were joined by one of our specialists in the field of developmental disabilities.

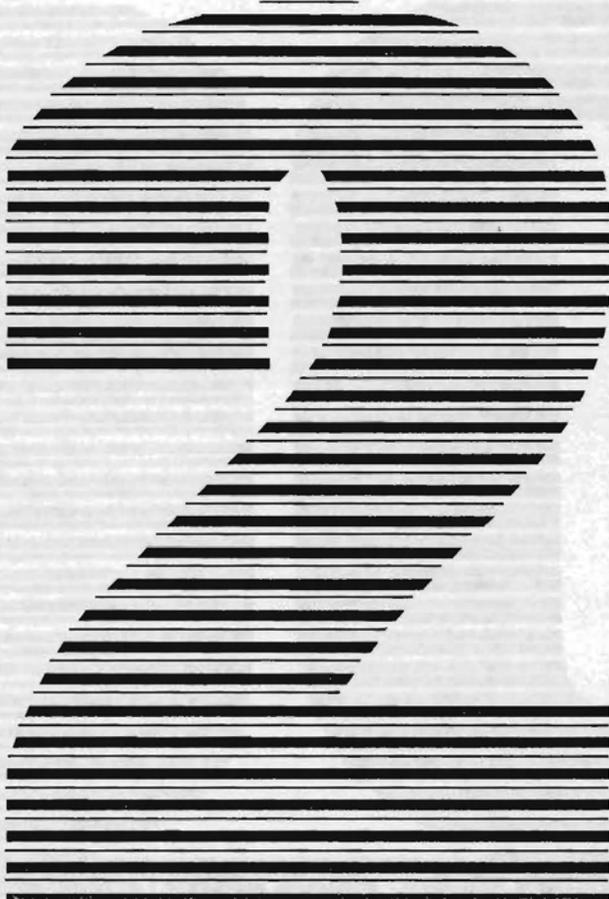
Small groups were formed to focus on six areas:

- Early Intervention/Education,
- Family Support,
- Children with Complex Needs,
- Empowerment,
- Employment, and
- Supported Living.

The groups were challenged to think creatively about the future barriers that prevent reaching their vision of the future. Once they developed their own scenarios and identified barriers to the vision, they developed recommendations for action.

This report is a compilation of the small group work. In the first part of this report (*The Dream Denied*), the dream of the Lanterman Act is presented. The second section (*A New Vision*) presents the people's dream of what California should be like by the year 2000. To achieve this dream, obstacles identified in the third section (*It Won't Be Easy*) must be overcome. Thus the fourth section (*There's Work To Be Done*) identifies a formidable set of actions we must take over the next decade.

NEW DIRECTIONS FOR A NEW DECADE



BY THE YEAR 2000

EMPOWERMENT

Individuals with disabilities will speak for themselves with assistance as requested; professionals will listen to people with disabilities and their families, and the provision of services will respond to the needs expressed.

People with disabilities will live, work, learn, and play in settings of their choosing. Individuals with disabilities and their families will make informed choices, take risks, accept responsibility and exercise their full civil rights.

People with disabilities and their families will be involved at all levels of leadership. People with disabilities and their families will be involved in all decisions that affect their lives.

The spirit of the Lanterman Act will be enforced; self-determination will be included and funded in the Act.

NEEDS

California will provide all necessary resources to prevent developmental disabilities.

California will provide all necessary supports to children with special needs in order that they may live in a family/home environment.

SUPPORT

Individuals and their families will identify their own needs and have resources to meet them.

EARLY INTERVENTION / EDUCATION

Every child in California will attend his/her neighborhood school (or school of choice) and participate in neighborhood and community activities, with the necessary support to facilitate this goal.

Infants and children with special needs will receive comprehensive services that are designed to meet their needs.



**The Lanterman
Developmental Disabilities
Services Act—
A Dream Articulated:**

In 1977, the State of California passed what is known as the Lanterman Developmental Disabilities Services Act.

The Lanterman Act held great promise for changes in the way services would be developed and delivered for Californians with developmental disabilities.

The Lanterman Act articulates a dream because:

- It recognizes rights—"the same legal rights and responsibilities guaranteed all other individuals";
- It calls for services which would "enable persons with developmental disabilities to approximate the pattern of everyday living available to nondisabled people of the same age";
- It defines program effectiveness in terms of "more independent, productive, and normal lives for the persons served"; and
- It calls for a continuum of services "sufficiently complete to meet the needs of each person with developmental disabilities, regardless of age or degree of handicap, and at each stage of life."

The Act created the State Council on Developmental Disabilities, Area Boards on Developmental Disabilities, and Regional Centers—to ensure coordinated planning, regional monitoring of services, and a network of services accessible to every family in need.





As a Response to Challenges and Barriers

The Lanterman Act spells out a number of legislative findings which defined some of the challenges facing individuals with developmental disabilities, their families and the service system.

The Legislature found that:

- the mere existence or delivery of services is, in itself, insufficient evidence of program effectiveness;
- the legal, civil, and service rights of persons with developmental disabilities are frequently denied, and that there is no effective method for planning and coordinating the state's resources to assure these rights;
- whenever multiple, uncoordinated, and duplicative planning activities are conducted by different state agencies on behalf of persons with developmental disabilities, the result is confusion of responsibilities, a lack of systematic priorities, and failure to make the most appropriate use of all federal, state and local funds and programs;
- there is a shortage of programs and facilities to provide a comprehensive network of habilitation services to persons with developmental disabilities throughout the state; and
- the method of appropriating funds for numerous programs for the developmentally disabled affects the availability and distribution of services and must be related to statewide planning.

Lanterman 2000—Old Challenges, New Dreams

The purpose of the Lanterman 2000 conference was to identify ways to revitalize the dream of the Lanterman Act. People came together recognizing that many parts of the Lanterman dream are still valid and that the realities to which the Lanterman Act was intended to respond are all too frequently with us today. And they articulated a new dream—a dream for Californians, with and without disabilities alike. A dream to give direction to state, community and individual action. A dream for the year 2000.

VISION STATEMENT

EMPOWERMENT

By the year 2000, individuals with disabilities will speak for themselves (with assistance as requested), professionals will listen to people with disabilities and their families, and services will respond to the needs expressed.

By the year 2000, people with disabilities will live, work, learn, and play in settings of their choosing. Individuals with disabilities and their families will be making informed choices, taking risks, accepting responsibility and exercising their full civil rights.

By the year 2000, people with disabilities and their families will be significantly involved at all levels of leadership as elected officials, policy-makers, and administrators. People with disabilities and their families will be involved in all decisions that affect their lives, regardless of anyone's view of their worth or competency.

By the year 2000, the spirit of the Carter-Vesco Act will be enforced; self-determination will be included and funded in the Act, and the Act will be updated to address adult issues.

PREVENTION/CHILDREN WITH COMPLEX CARE NEEDS

By the year 2000, California will provide all necessary resources to prevent developmental disabilities.

By the year 2000, California will provide all necessary supports to enable children with special needs to live in a family/home environment.

FAMILY SUPPORT

By the year 2000, individuals and their families, regardless of disabilities, culture, ethnicity or religious belief, will identify their own needs and have resources to meet them, so that all people grow up in families that believe they are great, and in communities that believe that these individuals are valuable.

By the year 2000, California's communities will include people with developmental disabilities as full citizens. Individuals with developmental disabilities will be recognized, accepted and welcomed as a normal part of the fabric of the communities.

This future must include each of the following:

- Individuals with disabilities speaking for themselves,
- Professionals listening to and seeking the advice of individuals and their families,
- Services responding to what individuals with disabilities or their families say they need,
- Individuals with disabilities and their families making informed choices, taking risks, accepting responsibility, and exercising their full civil and human rights,
- Individuals with disabilities and their families assuming power and responsibility in political and administrative arenas,
- Children with disabilities and their families receiving the support they need to stay together as a family, if they choose,
- All children with disabilities living in families,
- Children and adults with disabilities living in environments which best promote their growth, development, and happiness; ensure stability; provide a high quality of life; and meet their changing needs,
- Children and adults with disabilities living in communities which see them as valuable people,
- All children with disabilities, going to school and participating in their neighborhood and community life together,
- People with disabilities living, working, learning and playing in community places with community people, and
- Everyone with developmental disabilities who want to work will work.

All of this means designing and developing services and supports which:

- Respond to the expressed desires of the individual and/or their families, rather than the types and amount of service available in a community,
- Assure that individuals and families make choices, create options, and act on their own behalf, rather than having to rely solely on the options and funding available through agencies,
- Focus on assisting individuals with a developmental disability to be a member of the community, rather than merely a client in services, or someone who is moved apart from the community, and
- Realign its priorities to ensure that individuals with disabilities remain in the community and/or return to the community from institutions.

Once the Lanterman 2000 participants developed a vision of the future, they identified existing barriers to realizing the vision.

The barriers identified related to specific vision statements and in all, thirty five barriers were identified in the six vision areas as standing in the way of achieving the vision. There is considerable overlap among these areas. The following summarizes the barriers into eleven general statements and the detailed statements from small groups are clustered under the more general statements.

Lanterman 2000 Barrier Statements

- **The system is unresponsive, uncoordinated, inflexible, and not accountable.**

“The system meets the needs of the bureaucracy and not the needs of the families and individuals.”

“The system doesn’t ask, listen, and neither does it act.”

“Lack of coordination and inflexibility of services.

“Inflexibility in the system.”

“A lack of coordination among the multiple systems with multiple regulations.”

“The current system, its design and operation does not totally support children and families.”

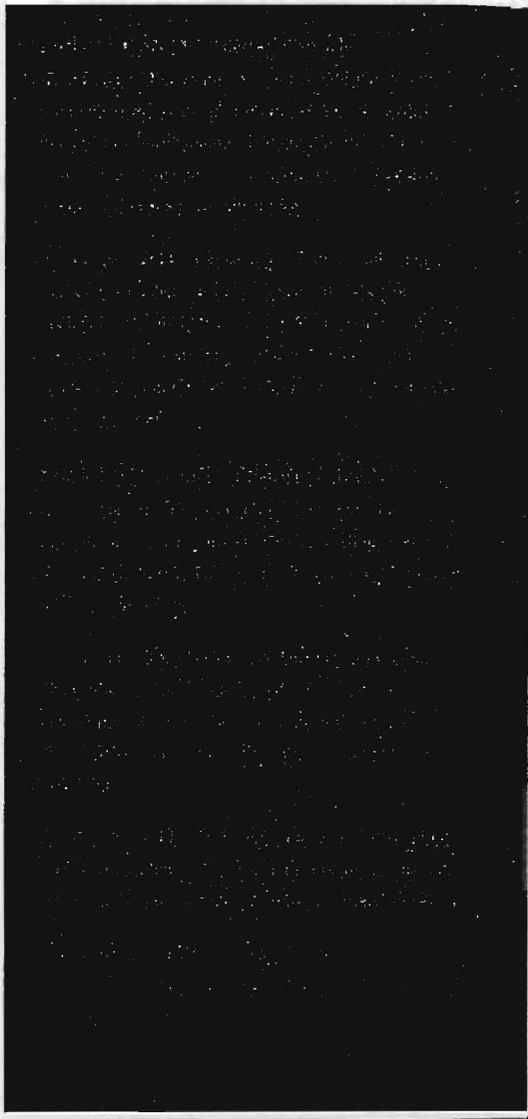
“There is a lack of human resources available to meet needs of children and families.”

“Lack of legal accountability in enforcing the Lanterman Act.”

- **The system is insensitive and unresponsive to the multi-cultural and multilingual reality of California.**

“Insensitivity and unresponsiveness to the values and needs of a multi-cultural, multilingual population. Examples include:

- Lack of trained professionals to address needs,
- Lack of creative/effective outreach, educational programs,
- Lack of choice/resources, and
- Non-compliance with existing federal and state civil rights laws.”



**THE SYSTEM—PUBLIC POLICY,
FUNDING, AUTHORITY AND
SERVICES—IS NOT RESPONSIVE
TO INDIVIDUAL NEEDS, OR
SUPPORTIVE OF INDIVIDUALS
AND FAMILIES.**

OUR VISION OF THE FUTURE IS NOT SHARED BY ALL OR KNOWN TO THE GENERAL COMMUNITY. IT IS NOT EXPRESSED IN PUBLIC POLICY.

■ **Funding and services are not sufficient or organized to respond to individual needs.**

“Lack of capability to provide support services for each person to keep their job.”

“The consumer does not control funding or the choice.”

“Lack of consumer control of resources.”

“Funding is inconsistent with what people need, value and care about (human needs are not given priority when establishing funding).”

“Categorical funding limits creativity and flexibility to meet individual needs.”

“Is it the lack of creativity or the lack of flexibility in funding?”

“Lack of necessary funding.”

■ **There is a lack of public and policy awareness.**

“The citizens of California do not have sufficient awareness to want to take responsibility for eliminating these barriers and creating solutions.”

“Lack of public policy, public awareness, and support for this concept.”

“Lack of a clear vision by all.”

“There are negative attitudes by society towards people with special needs.”

■ **Individuals and families are not yet effectively politically organized to change this.**

“Lack of an organized political effort on the part of the consumers, families, advocates, professionals to influence effectively the governor, state staff and legislature.”

“Lack of involvement and participation on the part of people with disabilities in the political process.”

■ **They have been kept apart.**

“Segregation.”

“Lack of adequate technology communication devices, and accessibility and transportation.”

“Social isolation and alienation.”

“Children with developmental disabilities are denied basic rights (a separate education is not an equal education).”

■ **As a result, individuals with developmental disabilities and their families may feel powerless, alone, and fearful.**

“Poor self esteem.”

“Lack of peer support systems.”

“Fear of retribution for speaking out about problems.”

“Fears about working (losing SSI and MEDI-CAL, lower self-esteem, no established work ethic).”

THERE IS A LACK OF COMMITMENT TO AND RESPONSIBILITY FOR PREVENTION.

“Not enough of a commitment to prevention within the developmental disabilities system.”

“Lack of agreement on responsibility for prevention education.”

THE WAY IN WHICH INDIVIDUALS WITH DEVELOPMENTAL DISABILITIES LIVE THEIR LIVES HAS KEPT THEM FROM BEING KNOWN BY THE COMMUNITY AND PART OF THE POLITICAL PROCESS.





The small groups met throughout the Lanterman 2000 conference continually to refine their statements of vision and barriers and develop a series of recommendations in each vision area. These recommendations are intended to address the barriers, and move positively toward implementing the vision statements. While small group work focussed on each of the six vision areas resulting recommended actions overlapped one another. Together, however, they create a powerful series of agendas for action.

The recommendations comprise the following agendas:

- **Constituency Building,**
- **Legislative and Policy,**
- **Empowerment,**
- **Support Choice, Inclusion and Individual Planning,**
- **Prevention,**
- **Multi-Cultural Recognition, and**
- **Training and Development.**

Constituency Building

The intent of this agenda is to market the vision of the Lanterman 2000 conference, to enlist the support of a wide range of community and political constituencies, and to join in common cause with those who seek a similar future. Change will occur if forces are joined, the community understands the message, and decisionmakers know there is considerable and broadly based support for the vision.

An equally important result of building a constituency for the vision is increased understanding, acceptance, and welcoming of individuals with developmental disabilities by all kinds of people and organizations in the community.

This agenda reaches out to a wide variety of groups through a range of means:

- **Use of all types of media resources;**
- **Join forces with the Independent Living movement and other advocacy groups;**
- **Approach political leaders at all levels to inform and convince them, obtain their support, then enlist it;**
- **Organize grass roots movement for inclusion;**
- **Learn about the positions and experiences of others. Spread the good news, counter the bad;**
- **Reach out to community groups;**
- **Increase the visibility of people with disabilities in the community; and**
- **Reach out to and involve people who are outside of the disability community.**

A major component of the Constituency Building Agenda is voter registration and voting by people with developmental disabilities. Recommendations in this area for action are presented as part of The Empowerment Agenda.



Legislative and Policy Action

One major reason for marketing the vision is so it will be mandated via changing legislation, policy, funding and regulations. The recommendations coming out of Lanterman 2000 detail many changes either in legislation or policy. Whether expressed in terms of legislation, changes in funding, new patterns of planning, or different styles of regulations, the recommendations call for the following major changes:

- **Design, deliver and fund services and supports in response to what individuals and families say they need. Ask individuals and families what they want. Listen to what they say. Respond to what they say. Give them control over funding and the supports they need;**
- **Eliminate the dual (segregated/special and regular) system of education. Support children and young adults with developmental disabilities to participate in regular education programs, with young people their own age, in typical settings;**
- **Develop a family centered, culturally sensitive and flexible system of support to families. Embrace and enforce two statements—**
 “It is not an option to institutionalize children. It must be an option to provide necessary supports to keep a child at home.”
- **Provide case management services in such a way that they are truly supportive of individuals and families;**
- **Develop, direct and redirect funding in support of community living, individual choice, and family life;**
- **Adjust regulations, criteria, and definitions in support of the vision;**
- **Stand behind and support the concept of people with developmental disabilities living, learning, working, and playing in the community—to be not only present in the community, but to participate in the life of the community and develop relationships with other citizens;**
- **Support individuals to live in homes of their own choice, and assist them to integrate into the life of the community;**
- **Support individuals to find, obtain and retain employment, and to not suffer financially because they do; and**
- **Develop mechanisms for comprehensive local and state planning which actively involve local control and participation.**



Empowerment

The Empowerment Agenda involves ensuring that individuals with developmental disabilities and their families have a voice in issues and decisions which affect their lives. It seeks to actively and decisively involve people in the power equations of service and policy decisions.

- **Information and knowledge about entitlements, options, and power;**
- **Representation in decision making bodies related to the individual, services, and planning;**
- **Monitoring service quality;**
- **Formally recognizing the roles, responsibilities and powers of individuals, families, professionals and agencies;**
- **Assisting individuals and families to learn how to advocate on their own behalf and represent their own interests;**
- **Assisting individuals and families to work collectively to achieve their goals; and**
- **Individuals and families “managing their own cases” rather than relying on others to be case managers.**

Support Choice, Inclusion and Individual Planning

Many items on the Legislation and Empowerment Agendas are directed at supporting individual planning, the inclusion of people with disabilities in the life of the community, and exercising choice.

The primary features of the agenda include:

- **Guaranteeing that the consumer and family control and direct the system, and that individuals and families have the fiscal authority to implement their "life plans";**
- **Investing in case coordinators, facilitators and outreach workers to assist people to make their way into the community and develop relationships in the community;**
- **Developing networks of support for each individual, at work and in the community;**
- **Decreasing the complexity of the system, and increasing its sensitivity; and**
- **Ensuring that information is freely available to individuals and families about their options and entitlements.**

Prevention

The major elements of the Prevention Agenda are:

- **Public policy, coordinated action and priority attention;**
- **Allocation and redirection of funds;**
- **Comprehensive delivery of family planning, prenatal care, and family life and health education; and**
- **An understanding of the links between poverty and the occasion of disability, and taking action based on that understanding.**

Multi-Cultural Recognition

The issue of sensitivity to the multi-cultural realities of California came up in a number of areas. The agenda for respect includes:

- **Cross cultural training, outreach and information;**
- **Empowerment of ethnic groups and the creation of a multi-cultural, multi-ethnic coalition; and**
- **Acceptance and recognition of multi-cultural/ethnic values in planning, service delivery, resource allocation, and decision making processes.**

Training and Development

In each of the vision areas, it was recognized that many people need information, knowledge, skills, advice, consultation, support and encouragement to learn new skills, respond to new demands, plan ahead, and work with people in partnership. The Training and Development Agenda is directed at individuals with disabilities, families, professionals, decisionmakers. Some of the priorities include:

- **General knowledge for consumers, parents and professionals;**
- **How to influence legislators;**
- **Permanency planning and the parents' perspective;**
- **Technical assistance in supported community living;**
- **All employment and disability services;**
- **Leadership development, self-advocacy;**
- **Peer support, role models;**
- **New models of service that foster independence and empowerment; and**
- **How to empower people.**



The agenda includes not only targets and topics for training and development. It also includes funding and support for people to participate.

And Together We Will Work Through These Agendas.

We came together at Lanterman 2000. Together, we developed a vision of what California should and will be over the next decade. Our vision is a dream and this dream will not be denied. We recognize the barriers and obstacles which stand in our way. We respect the strengths, capacities, creativity and resources of our communities. There is work to do. Our agendas are not modest. And, together, we will make it happen.

**CONSTITUENCY BUILDING—
INFORMATION, PERSUASION,
COALITION, AND POLITICAL
ACTION**

- **Increase the visibility of people with disabilities living, working, learning and playing in the community. Public education coordinators employed by regional centers will be responsible for:**
 - Articles in the newspaper,
 - Public service announcements (Radio and TV),
 - Appearances and interviews in the media,
 - Presentations to business and service organizations, and other civic groups,
 - Sponsorship of public awareness events,
 - Coordinating media watch (acknowledge positives, respond to negatives), and
 - Ensure that disability awareness programs are fully implemented and that speakers bureaus include people with disabilities of all ages.

- **Use local cable, public and commercial TV to educate public.**

- **Build community by reaching out to people outside of the disability community.**

- **Convene Lanterman 2000 annually.**

- **At the next Lanterman 2000 conference, each person will invite one person not involved in the disability system. The invitees will represent California's diversity.**

- **Everyone at Lanterman 2000 will meet with legislators, and share the current state of services for individuals with developmental disabilities and the mission statements of Lanterman 2000.**

- **Engage political leaders in meaningful dialogue about the rights and needs of persons with developmental disabilities.**

- **Ask political candidates about their positions on disability issues.**

- **Create a coalition of parents, consumers, professionals, and providers. To the extent possible, develop a platform for realizing the vision. Participants of this conference will build a grass roots type movement.**

- **Assembly Office of Research Study to look at where all employment related money is going and what outcomes are achieved: ARCA and Area Boards take the lead in assembling a consortium of key advocacy groups to make a consensus recommendation to Senator McCorquodale that this study be accomplished as part of SR-9 process.**

Share the Vision

- Share the vision everywhere with everyone (support groups, school boards, SELPA, community groups, educators, parents).
- Spotlight successful examples of the Vision already in existence.
- Gather specific information on Vermont Model, and specific examples in California where special/regular education have been coalesced into one. Put together a "how to do it".
- Present on radio talk shows.
- Continue working on integration consortium.
- Go to local school districts to discuss integration.
- Keep in touch with fellow committee members. Assist anyone who asks in establishing an integration consortium in the county.
- Celebrate what is good/successful.
- Focus on addressing needs of all children.
- Make use of media resources—Public Service Announcements, Letters to editor, Talk Shows.

Stir Things Up

- Develop mailing/phone list of group attending Lanterman 2000.
- Talk with local educators in order to identify specific concerns relating to the elimination of the current dual system. Work with them around issue of one education system. Talk with special educators about benefits of one system.
- Contact local school superintendents about collapse of dual system. Contact local school principal to determine what is needed for kids with special needs to be a part of the general education and after school programs. Measure response, elicit reasons will/not work, leave with one plan of action. Do it.
- Meet with the following groups to present the vision. Measure their responses. Find out why they think it will or will not work.
 - Local PTA Council
 - My own parent support group
 - Local parent groups
 - Area Boards
 - Regional Center boards
 - School board staff and trustees.

BUILDING A CONSTITUENCY, NEXT STEPS—EDUCATION



- **Share the Employment vision using peer marketing:**
 - parents to parents,
 - agency to agency,
 - employed individuals to those in day programs, and
 - employer to employer.

- **The developmental disabilities community should work with the Independent Living movement to achieve our goals for support services.**
 - Work with California Foundation of Independent Living Centers to discuss areas of mutual concern and how to use existing support structure.
 - Work with CFILC to secure passage of American with Disabilities Act.
 - Work with residential care providers to resolve problems at the local level.
 - Form a paperwork task force to identify local support service problems and solutions.
 - Look at effectiveness of vendor systems.

- **Support People First to work with the Developmental Disabilities Action League and other groups to further political activism.**

- **Request a tax return checkoff for donations: refer to People First to be considered for their action agenda.**

- **ARCA request Department of Developmental Services and Department of Rehabilitation to publish a financial report identifying administrative costs related to total budget allocations.**

- **Medicaid Reform: Join other states that are experts or knowledgeable with political processes and are experts or knowledgeable on SSI regulations.**

- **Join already existing advocacy groups working on the issues,**

- **Parent action council with similar goals form a political Action Committee.**

- Attend meeting/s about high school closure and ask why they are not considering students with special needs.
- Attend and testify at LAUSD, LRE public hearings, SR-9 hearings re: school integration, PL 94-142 Review Hearings and testify.
- Activate local Autism Society Chapter—Regional Center parent group.
- Letters to editor.
- Through involvement with advocacy groups, AAMR, Area Board, CACs, etc. express concerns about dual system.
- Talk with parents during IEP meetings re: one system.

Get Smart About What's Happening

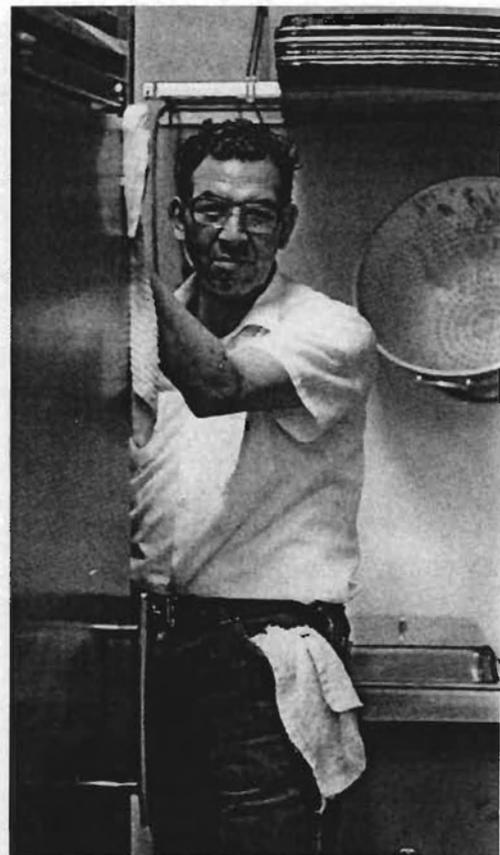
- Learn which school districts are seeking direct funds for meeting needs of special needs kids, talk to superintendents, find how our vision fits with their vision.
- Check with students in special education and see how they feel about their respective educational experience.
- Develop expertise within supporting groups on such things as funding.

Join With Others

- Continue CAC leadership with full intent of the spirit of the law.
- Start an integration consortium.
- Outreach (not training) to community groups—for instance, Kiwanis, PTA, Chamber of Commerce.
- Establish and make use of existing local and statewide political networks, community networks.
- Parent Professional Partnership , etc. to:
 - have legislative teas,
 - prepare news releases,
 - contact media, and
 - speakers group to go to community and present to clubs.
- Form coalition of local special ed professionals to address issues (ongoing).

Infiltrate the System

- Get on local school board and Area Board.



**LEGISLATIVE AND POLICY—LAW,
POLICY AND FUNDING IN
SUPPORT OF THE VISION**

Get Legislators On Side

- **Visit and meet with local, state and federal legislators. Lobby for change. Take them to homes and programs.**
- **Explain and market what now exists and what the vision is.**
- **Phone/letter campaigns.**
- **Disability awareness and sensitivity training for legislators, entire community.**
- **Help get adults with developmental disabilities to vote.**
- **Change the legislators (consumers run for office).**

- **Amend the Lanterman Act to:**
 - Guarantee that the consumer and family direct the system.
 - Guarantee that consumers and families have the fiscal authority to implement their "life plans".
 - Guarantee that consumers and families are be educated about their entitlements and provided the opportunity to develop skills in decision making.
 - Enable the regional centers to use any residential funds and resources for individuals with developmental disabilities to provide personal care and supervision and necessary staff support in the community in homes of their choice.

- **Put a cap on funds to segregated services. Redirect resources to integrated services. ARCA and Area Boards to take lead to develop a consensus recommendation to forward to Senator McCorquodale to insert this action into Budget Act language for 91/92.**

- **Introduce (DD Council, Area Boards, PAI) legislation to assure that agencies with statutory advocacy responsibilities are independent of other state agencies, and have the authority to carry out their responsibilities.**

- **In state legislation, guarantee security, permanence, choice, options and quality for individuals with developmental disabilities during all stages of life.**

■ **State legislation:**

- DDS shall expand its Medicaid Reform to include the ability to support individuals and families in the community, and
- All current and new dollars for residential services may be redirected to these efforts. Redirect public dollars spent on institutions.

■ **Develop a block grant funding mechanism to cover all regional services, including state developmental centers. These monies will be distributed through an equitable system of local control.**

- Establish equitable form of funding distribution to regional centers using all money coming into the system with local regulations, this includes state developmental centers.
- DDS will run hospitals with money coming through regional centers. They will also hold contracts with regional centers. Regulations will be made by regional centers not DDS.
- There will be a pot of money that guarantees training forums for consumers, parents and providers.

■ **Develop legislation to provide that funding for support services go directly to the individual. A comprehensive sole funding and referral source for support services.**

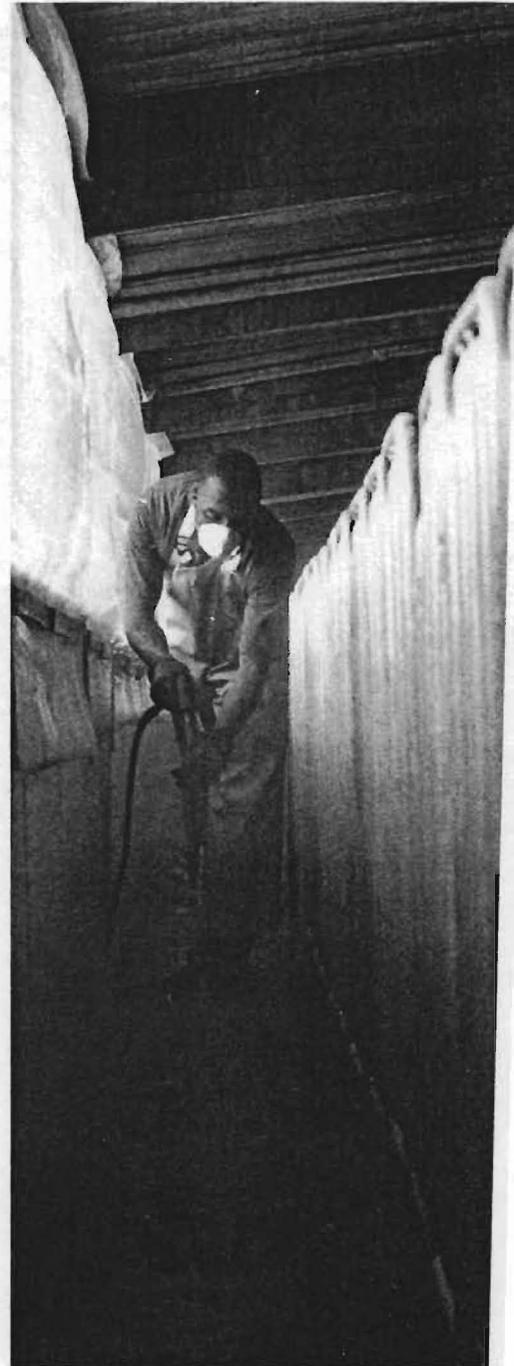
■ **Remove the following from Regional Centers—purchase of service review function, the funds and accounting function.**

■ **Eliminate vendorization regulations.**

■ **Funds need to be available to offer stipends and training time for service providers.**

■ **Salaries should be adequate and competitive to attract staff. Need to equalize pay for program staff at same level as regional center and state developmental centers employees.**

■ **Adequate payment for services—actual cost reimbursement. Funding should be based on performance. Performance to be evaluated by an independent system of consumers and parents.**



Children and Families

- **Development of family centered, culturally sensitive and flexible in-home support system. Immediately initiate a family subsidy program based on need. Direct the Secretary of Health and Welfare. "It is not an option to institutionalize children. It is not an option not to provide necessary support to keep a child at home."**
- **Funding, including family subsidies, must follow the individual. Take whatever steps are necessary to ensure that children live in homes (if they choose). Redirect private and public funds used to support the institutionalization of children.**
- **Expand and change definition of "family".**
- **Decrease caseloads to 1:18 or lower. The state should give families and individuals either money or vouchers to directly purchase family needs identified by family/individual, the significant others, and a client program coordinator. The program coordinator's role is to ensure the above and to support and strengthen the family units to coordinate single entry services.**
- **Fund at least one parent to parent/family resource service in each county.**
- **Move control of funds to families through vouchers, subsidies, creative housing options.**
- **Broaden and apply developmental disabilities eligibility consistently.**
- **Availability of "insurance" for special needs children in their own homes. Support a national health plan. Reform of private insurance industry to cover special needs children.**
- **Elimination of medical model (waiver) mentality.**
- **Develop a partnership between primary care-giver and professional in determining needs and services. Regional centers should meet with families to change all IPPs to add necessary services to keep children at home. Funding must follow according to Lanterman Act.**
- **Adjust Gann Initiative on the June ballot. Work with broad coalition to accomplish.**

- **Develop a comprehensive plan of services for children with special needs to be done by Area Boards. Local planning chapters, with an overall state umbrella, formed from local areas (as determined by local representation) to include broad base of consumers, medicine, education, social services, regional centers, ARC, Medi-Cal, health services, advocacy groups, etc. To be developed over the next 12-18 months.**

Education and Involvement

- **Eliminate the dual system of regular and special education.**
 - Stop placing children in special segregated settings.
 - Educate districts about least restrictive environment (LRE).
 - Provide full spectrum of individualized education for all children in schools according to the children's needs
- **Recognize in policy that:**
 - Resources, services and activities within neighborhoods and communities will be available to all citizens.
 - Early and full participation in the community is essential.

Supported Living

- **Funding will be flexible and respond to consumer support and service needs:**
 - Unused CPP and PDF money for 89/90 and all new CPP and PDF money will be committed to supported living.
 - Medicaid waiver funds will be changed to offer individualized funding for personal support alternatives (as Colorado did).
- **All regional centers will have the opportunity to develop supported living services utilizing any existing funds in new ways.**
- **Develop legislation requiring all housing development to be integrated and accessible.**
- **DDS, Health Services, and DSS to be involved with the community in changing the law with regards to care, plus supervision regulations to allow individuals to live in their own homes by July 1, 1991.**

Employment

- **Regulations related to employment should allow ease, and effectiveness. One step approach and lack of hassles.**
- **Public input to OAL may be ineffective in modifying the proposed DDS day program regulations. Class action litigation should be considered on the ground that the regulations are in conflict with the Lanterman Act, discrimination and equal treatment.**



EMPOWERMENT—HAVING A VOICE AND A SAY

- Redraft regulations which support people with disabilities to work and be in the community.
- Recommend a pilot project to test a voucher system. Regional Center would issue vouchers to be used by consumers to purchase employment training or coworker support. Initial placement to be made by a vendor to conduct assessment.

Control and Authority in Individual Planning

- Guarantee that consumers and families have the fiscal authority to implement their “life plans”.
- Guarantee that consumers and families shall be educated about their entitlements and shall be provided the opportunity to develop skills in decision making.
- Implement that portion of the Lanterman Act that allows individuals to serve as their own case managers. Provide support and oversight as needed.
- Implement that portion of the Lanterman Act that allows parents to be their child’s case manager if they so choose. Develop mechanisms for support and oversight.
- Parents and providers need written agreements on mutual responsibilities and commitments as equal partners.

Representation of Consumer Viewpoints

- When you develop recommendations in conferences like Lanterman 2000, ask People First and other consumer organizations to do things, rather than saying they will do them.
- Within three months each regional center will have a consumer advisory council.
- Within six months (or next vacancy) each regional center will have at least one primary consumer on their board, elected by the Consumer Advisory Council. Facilitation and transportation will be provided.
- Within five years, each regional center board will have 25-50% primary consumers.
- All local and state boards and committees will be comprised of 51% individuals with disabilities or families.

- **Regional Centers should have paid consumers and parents on staff to address respective issues.**
- **Consumer monitoring. Bi-weekly consumer advisory committee meets with the director(s) of Department of Developmental Services, Department of Rehabilitation and/or the involved agencies. Consumers will evaluate their own programs.**

Leadership Development

- **Leadership development for children, adults and families including:**
 - Resources shall be directed toward self-advocacy. This includes provisions to reimburse primary and secondary consumers.
 - Professional/Parent support groups must be developed on “how to let go”
 - Consumers will help other consumers make decisions. Finally support will be guaranteed to provide all necessary supports to maximize consumer participation.
- **Provide information to families and assistance and support when requested, regarding opportunities to participate in leadership conferences, support groups, advocacy activities in their communities.**
- **Provide respite support to families to encourage and facilitate their participation in community advocacy activities.**
- **Develop skilled peer program to assist with social and leadership development. Develop transportation and facilitation. (Peer = someone who is of same age and interests, with or without disability).**
- **People who work with children with developmental disabilities will receive instruction on how to empower children.**
- **Adult role models will come into schools and work directly with children with developmental disabilities.**
- **Awards will be given to children who show leadership growth.**
- **Develop parent-parent support program to assist parents in “letting go” and empowerment.**



Self Advocacy

- **All Area Boards shall develop Self Advocacy instruction and groups in their areas by 1992.**
- **Each board will be allocated one full time position to develop and support self-advocacy activities within their catchment area by 1991-92**
- **Allocations and scholarship funds will be established to support self advocacy activities.**

Voter Registration

- **People First and other groups should be supported/asked to undertake a massive voter registration of people with developmental disabilities, and assist in Census 1990**

Outreach:

- At every IPP, the consumer should be asked if s/he is registered to vote. Assistance should be offered in terms of voter education, transportation, absentee ballots, etc.
- Voter registration booths at People First conference in Redding (March), San Diego (June), and Los Angeles (October).
- Monitor how many people are eligible to vote in Regional Centers, DDS.
- Work to assure full participation in the Census.

SUPPORT CHOICE, INCLUSION AND INDIVIDUAL PLANNING

- **Guarantee that consumers and families have the fiscal authority to implement their “life plan”.**
- **Guarantee that consumers and families shall be educated about their entitlements and shall be provided the opportunity to develop skills in decision making.**
- **Secure funding to meet needs.**
- **Purchase of service will be consumer governed.**
- **Quality assurance is driven by the Individual Family Plan.**
- **Privacy, social, and sexual needs of the individual must be considered.**
- **Invest in facilitators to ensure successful inclusion into communities.**
- **Integrate individuals with disabilities into schools, work places, housing, transportation, recreation etc.**
- **Increased availability of community, integrated services for persons with developmental disabilities in non-congregate and non-facility based setup.**
- **Implement in the individual’s community a people-to-people network. An outreach worker would be assigned.**
- **Flexibility of services is needed to meet the changing needs of children and families.**
- **Provide one step eligibility and assessment procedures.**
- **Services must be sensitive to family values.**
- **Increase local control over delivery system.**
- **Reduce case coordinator load to 1:18.**
- **Adults with disabilities should be available as resources provided to adults and children.**
- **Provide public information, outreach and education about the rights, needs, capabilities of individuals with disabilities.**
- **Provide videos (in several languages) informing people about community resources. Every public and school library should maintain a disability collection.**

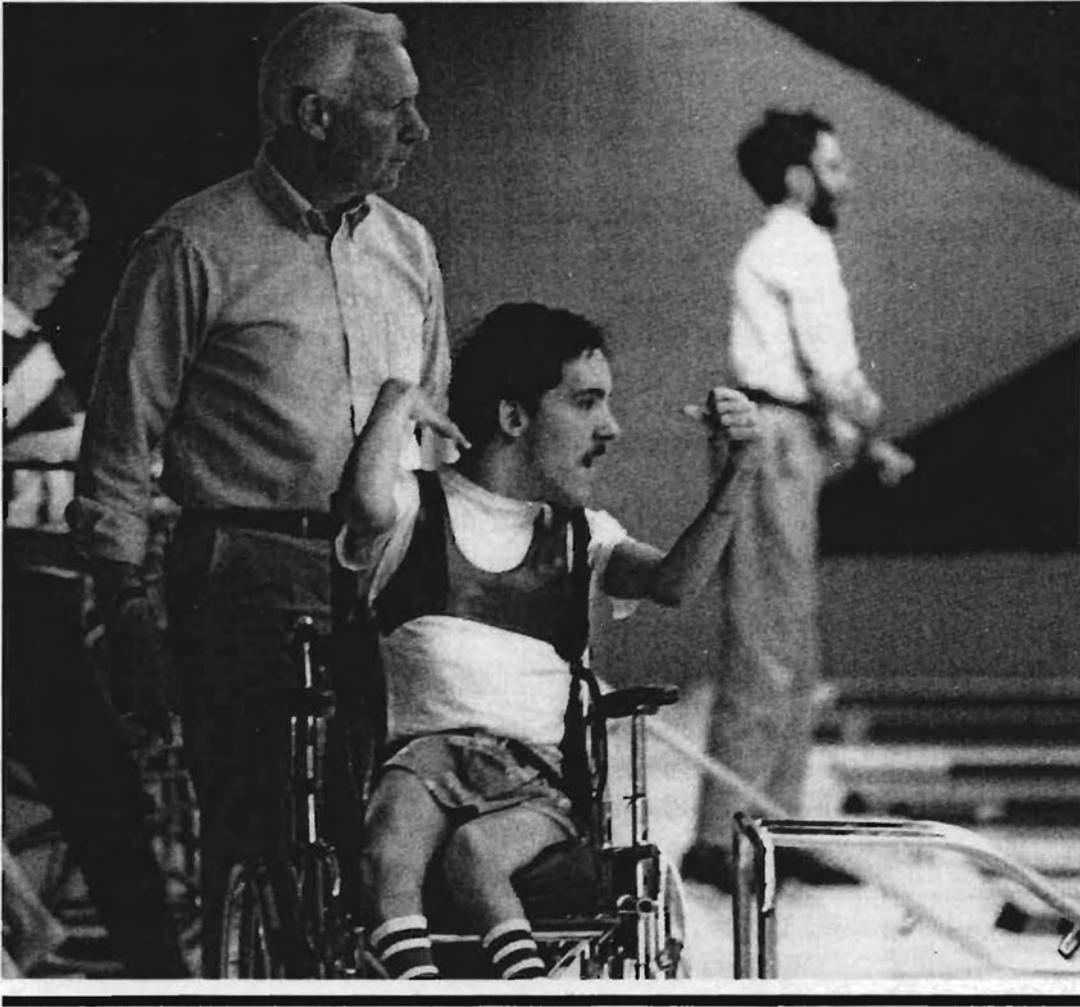


PREVENTION—PLANNING, PRIORITY, RESOURCES

- Consolidation and coordination of prevention plans, efforts, resources across the system through the establishment of a state wide interagency coordinating council (similar to PL99-459). The council will represent consumers, ethnic and age groups.
- Aggressive implementation with existing resources and expansion of new sources through state income tax donations, a percentage of environmental pollution fines, and a non profit foundation attached to the council.
- Establishment of clear public policy and high priority by the State of California to prevent developmental disabilities.
- Planned redirection of treatment expenditures to prevention activities and expanded use of private sector resources for prevention efforts.
- Comprehensive family planning and prenatal care available for all regardless of income. Family Planning will receive full and ongoing funding.
- Local planning, incorporating consumer input into prevention activities.
- Mandated, culturally-sensitive, family life and health education curricula from K-12 grades. Implementation should be tied to funding. Local communities must be involved.
- Creation of link between prevention and poverty issues by development of a long term data base to document relationships.

MULTI-CULTURAL RECOGNITION—RESPECTING THE REALITY

- Develop creative education and communication approaches at all levels—individual, families, professionals, public at large—through:
 - cross cultural training of professionals. Increased recruitment and retention efforts of minorities in developmental disabilities and health fields;
 - development of multimedia resources (videotapes) specific to multi-cultural and ethnic populations
 - empowerment of ethnic groups.



- Development of positive role models through leadership training.
- Development of multi-cultural/ethnic coalition that recognizes the integrity of cultural values and needs, and that would educate and monitor agencies, advocates, etc. on behalf of multi-cultural/ethnic populations.
- Implementation of the spirit and intent of the Lanterman Act.
- Include the Department of Developmental Services Long Range Plan/SCDD Plan, Area Board and Regional Center Resource Plans, and all other agency agreements to address multi-cultural/ethnic needs.
- Acceptance at state and regional center levels of multi-cultural/ethnic values and needs translated into activities.
- Target and redirect resources to reflect multi-cultural/ethnic needs.
- Board representation should reflect population they serve.

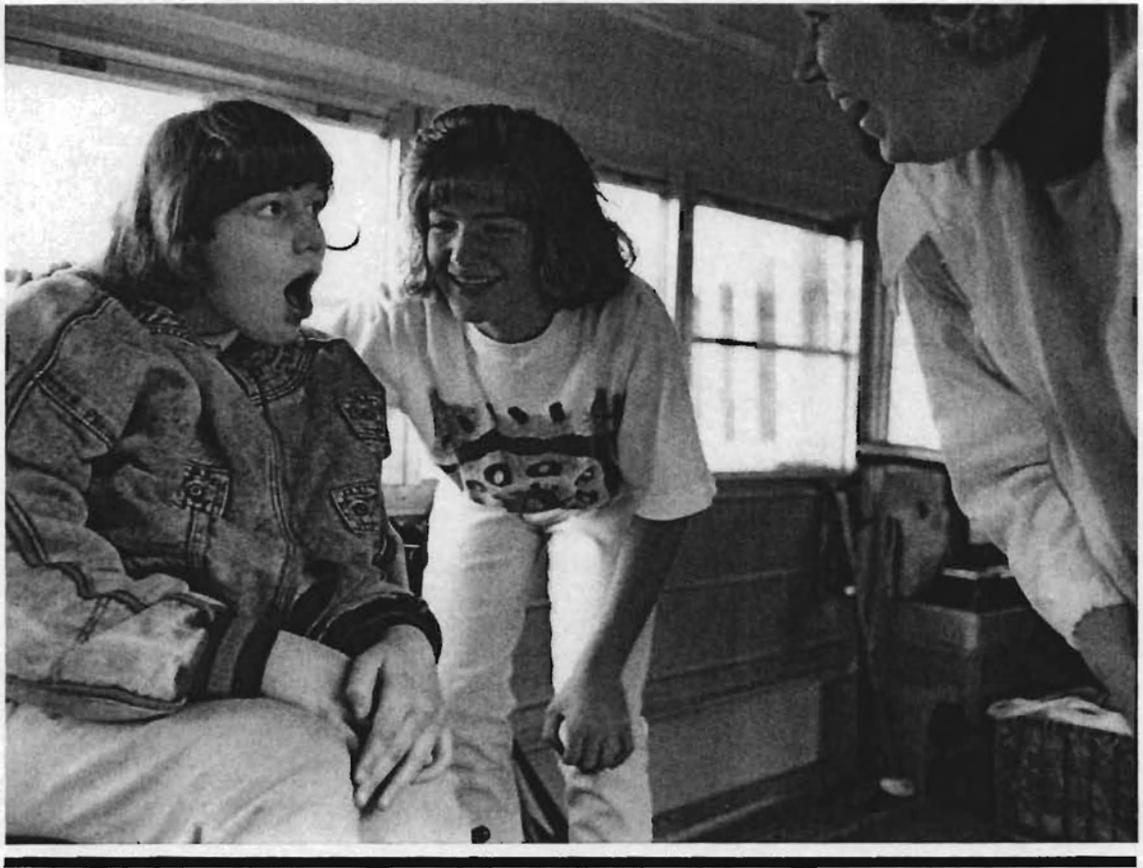
**TRAINING AND DEVELOPMENT—
PREPARING FOR CHANGE, NEW
SKILLS, NEW POWER**



- Training and education of families of children with special needs.
- Provide more education for consumers, parents and professionals.
- Provide adequate information to families on how to access systems.
- Regional Centers shall develop and fund access to community leadership training opportunities which are integrated and designed for the general public. Facilitation will be provided.
- Develop and deliver professional retraining program, to include information on new models of services that foster independence and empowerment, and that include individuals with developmental disabilities as part of the training team.
- Develop parent/professional training program where parents and professionals have the opportunity to meet and speak with adults with disabilities who are succeeding in their lives.
- Individuals with disabilities, families and professionals should receive training on how to influence legislators.
- Professionals must receive mandatory training on permanency planning and parents' perspective.
- Regional Centers and Area Boards shall provide training to primary and secondary consumers regarding proposed changes in the Lanterman Act.
- Technical assistance by experienced supported living providers will be available to all Regional Centers and service agencies. This will be funded by DDS.
- Create a coordinated training effort that spans all employment and disability services.
- Provide knowledgeable, experienced physicians, educators, social workers, etc. with current information on service system.
- Increase training programs to provide access and initiatives to training and increase personnel pool.
- The State in partnership with universities should explore and assist funding for pre-service and higher education training programs from the federal government.



The Lanterman 2000 Steering Committee has met twice this year to discuss future plans. One of the decisions that has been made is that two reports will be generated from the January Retreat. The first report is attached and is a record of the proceedings of the January Retreat. We wanted to accurately reflect the views, comments, and visions expressed by the participants at the retreat. The Steering Committee did not feel that such a document fulfilled our original reason for the retreat, i.e., an action plan for the future of the developmental disabilities system in California. Therefore, in addition to this report, another is being developed that will be action oriented. It will answer the questions of where we want to go, how we will get there, what needs to be done, who will do it, how much will it cost, and a time frame for completion. We hope to have that report to the participants within sixty days of the receipt of this document. Rest assured your continued participation in this process is desired and critically needed. The Lanterman 2000 Steering Committee will continue to be in touch with you so that we may make your visions and ours a reality. Thank you for your commitment, dedication, and interest.



*“Our commitment for the
year 2000...empowerment,
support, education, work
and a home...”*

THE LANTERNMAN 2000
STEERING COMMITTEE

Dale Dutton
 Carol O. Kotkov
 David J. Kotkov
 Marian Hadley
 Lonnie Nolta
 Judy McDonald
 Marion Brooks
 Fran Smith
 Judy Corn
 Allen G. Evans
 Carol & Patsy
 Valerie Shambler
 Mike Danneker
 Michal C. Clark
 Sam Chan

Rosario Marin
 Carol R. Inman
 Frances Smith
 Mary Falvey
 Michael Long
 Laurie Shields
 Ralph M. Scheer
 Florene S. Poyadue
 Nancy Lopez
 Kenneth Nelsen

Marion Brooks	Mike Danneker	Marian Hadley	Nancy Lopez	Lonnie Nolta	Laurie Shields
Roger Chapman	Dale Dutton	Carol Inman	Mike Long	Florene Poyadue	Fran Smith
Michal Clark	Allen Evans	Naomi Karp	Rosario Marin	Carol Risley	
Judy Corn	Mary Falvey	David Kotkov	Judy McDonald	Ralph Scheer	
Sam Chan	Virginia Franco	Caroline Kotkov	Kenneth Nelsen		

L A N T E R M A N

2 0 0 0

P.O. Box 8152 Fox Hills
Culver City, California 90233-8152

